



General

Guideline Title

Autism. The management and support of children and young people on the autism spectrum.

Bibliographic Source(s)

National Collaborating Centre for Mental Health. Autism. The management and support of children and young people on the autism spectrum. London (UK): National Institute for Health and Care Excellence (NICE); 2013 Aug. 36 p. (Clinical guideline; no. 170).

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Recommendations

Major Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Care Excellence (NICE) (see the "Availability of Companion Documents" field for the full version of this guidance).

The wording used in the recommendations in this guideline (for example, words such as 'offer' and 'consider') denotes the certainty with which the recommendation is made (the strength of the recommendation) and is defined at the end of the "Major Recommendations" field.

General Principles of Care

Access to Health and Social Care Services

Ensure that all children and young people with autism have full access to health and social care services, including mental health services, regardless of their intellectual ability or any coexisting diagnosis.

Organisation and Delivery of Services

The overall configuration and development of local services (including health, mental health, learning disability, education, and social care services) for children and young people with autism, should be coordinated by a local autism multi-agency strategy group (for people with autism of all ages) in line with the NGC summaries of NICE guidelines [Autism: recognition, referral and diagnosis of children and young people on the autism spectrum](#) (NICE clinical guideline 128) (covering identification and diagnosis) and [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum](#) (NICE clinical guideline 142).

The assessment, management and coordination of care for children and young people with autism should be provided through local specialist community-based multidisciplinary teams ('local autism teams') which should include professionals from health, mental health, learning disability, education and social care services in line with the NGC summaries of the NICE guidelines [Autism: recognition, referral and diagnosis of children and young people on the autism spectrum](#) (NICE clinical guideline 128) (covering identification and diagnosis) and [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum](#) (NICE guideline 142).

Local autism teams should ensure that every child or young person diagnosed with autism has a case manager or key worker to manage and coordinate treatment, care, support and transition to adult care in line with the NGC summary of the NICE guideline [Autism: recognition, referral and diagnosis of children and young people on the autism spectrum](#) (NICE clinical guideline 128) (covering identification and diagnosis).

Local autism teams should provide (or organise) the interventions and care recommended in this guideline for children and young people with autism who have particular needs, including:

- Looked-after children and young people
- Those from immigrant groups
- Those with regression in skills
- Those with coexisting conditions such as:
 - Severe visual and hearing impairments
 - Other medical problems including epilepsy or sleep and elimination problems
 - Motor disorders including cerebral palsy
 - Intellectual disability
 - Severe communication impairment, including lack of spoken language, or complex language disorders
 - Mental health problems

Local autism teams should have a key role in the delivery and coordination of:

- Specialist care and interventions for children and young people with autism, including those living in specialist residential accommodation
- Advice, training and support for other health and social care professionals and staff (including in residential and community settings) who may be involved in the care of children and young people with autism
- Advice and interventions to promote functional adaptive skills including communication and daily living skills
- Assessing and managing behaviour that challenges
- Assessing and managing coexisting conditions
- Reassessing needs throughout childhood and adolescence, taking particular account of transition to adult services
- Supporting access to leisure and enjoyable activities
- Supporting access to and maintaining contact with educational, housing, and employment services
- Providing support for families (including siblings) and carers, including offering short breaks and other respite care
- Producing local protocols for:
 - Information sharing, communication, and collaborative working among healthcare, education and social care services, including arrangements for transition to adult services
 - Shared care arrangements with primary care providers and ensuring that clear lines of communication between primary and secondary care are maintained

Refer children and young people with autism to a regional or national autism service if there is a lack of:

- Local skills and competencies needed to provide interventions and care for a child or young person with a complex coexisting condition, such as a severe sensory or motor impairment or mental health problem, or
- Response to the therapeutic interventions provided by the local autism team

Knowledge and Competence of Health and Social Care Professionals

Health and social care professionals working with children and young people with autism in any setting should receive training in autism awareness and skills in managing autism, which should include:

- The nature and course of autism
- The nature and course of behaviour that challenges in children and young people with autism
- Recognition of common coexisting conditions, including:
 - Mental health problems such as anxiety and depression
 - Physical health problems such as epilepsy

- Sleep problems
- Other neurodevelopmental conditions such as attention deficit hyperactivity disorder (ADHD)
- The importance of key transition points, such as changing schools or health or social care services
- The child or young person's experience of autism and its impact on them
- The impact of autism on the family (including siblings) or carers
- The impact of the social and physical environment on the child or young person
- How to assess risk (including self-harm, harm to others, self-neglect, breakdown of family or residential support, exploitation or abuse by others) and develop a risk management plan
- The changing needs that arise with puberty (including the child or young person's understanding of intimate relationships and related problems that may occur, for example, misunderstanding the behaviour of others)
- How to provide individualised care and support and ensure a consistent approach is used across all settings
- Skills for communicating with a child or young person with autism

Making Adjustments to the Social and Physical Environment and Processes of Care

Take into account the physical environment in which children and young people with autism are supported and cared for. Minimise any negative impact by:

- Providing visual supports, for example, words, pictures, or symbols that are meaningful for the child or young person
- Making reasonable adjustments or adaptations to the amount of personal space given
- Considering individual sensory sensitivities to lighting, noise levels, and the colour of walls and furnishings

Make adjustments or adaptations to the processes of health or social care, for example, arranging appointments at the beginning or end of the day to minimise waiting time, or providing single rooms for children and young people who may need a general anaesthetic in hospital (for example, for dental treatment).

Information and Involvement in Decision-making

Provide children and young people with autism, and their families and carers, with information about autism and its management and the support available on an ongoing basis, suitable for the child or young person's needs and developmental level. This may include:

- Contact details for local and national organisations that can provide:
 - Support and an opportunity to meet other people, including families or carers, with experience of autism
 - Information on courses about autism
 - Advice on welfare benefits, rights and entitlements
 - Information about educational and social support and leisure activities
- Information about services and treatments available
- Information to help prepare for the future, for example, transition to adult services

Make arrangements to support children and young people with autism and their family and carers during times of increased need, including major life changes such as puberty, starting or changing schools, or the birth of a sibling.

Explore with children and young people with autism, and their families and carers, whether they want to be involved in shared decision-making and continue to explore these issues at regular intervals. If children and young people express interest, offer a collaborative approach to treatment and care that takes their preferences into account.

Families and Carers

Offer all families (including siblings) and carers verbal and written information about their right to:

- Short breaks and other respite care
- A formal carer's assessment of their own physical and mental health needs, and how to access these

Offer families (including siblings) and carers an assessment of their own needs, including whether they have:

- Personal, social and emotional support
- Practical support in their caring role, including short breaks and emergency plans
- A plan for future care for the child or young person, including transition to adult services

When the needs of families and carers have been identified, discuss help available locally and, taking into account their preferences, offer information, advice, training and support, especially if they:

- Need help with the personal, social or emotional care of the child or young person, including age-related needs such as self-care, relationships, or sexuality.
- Are involved in the delivery of an intervention for the child or young person in collaboration with health and social care professionals.

Specific Interventions for the Core Features of Autism

Psychosocial Interventions

Consider a specific social-communication intervention for the core features of autism in children and young people that includes play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person. Strategies should:

- Be adjusted to the child or young person's developmental level
 - Aim to increase the parents', carers', teachers', or peers' understanding of, and sensitivity and responsiveness to, the child or young person's patterns of communication and interaction
 - Include techniques of therapist modelling and video-interaction feedback
 - Include techniques to expand the child or young person's communication, interactive play, and social routines
- The intervention should be delivered by a trained professional. For pre-school children consider parent, carer, or teacher mediation. For school-aged children consider peer mediation.

Pharmacological and Dietary Interventions

Do not use the following interventions for the management of core features of autism in children and young people:

- Antipsychotics
- Antidepressants
- Anticonvulsants
- Exclusion diets (such as gluten- or casein-free diets)

Interventions for Behaviour That Challenges

Anticipating and Preventing Behaviour That Challenges

Assess factors that may increase the risk of behaviour that challenges in routine assessment and care planning in children and young people with autism, including:

- Impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes
- Coexisting physical disorders, such as pain or gastrointestinal disorders
- Coexisting mental health problems such as anxiety or depression and other neurodevelopmental conditions such as ADHD
- The physical environment, such as lighting and noise levels
- The social environment, including home, school and leisure activities
- Changes to routines or personal circumstances
- Developmental change, including puberty
- Exploitation or abuse by others
- Inadvertent reinforcement of behaviour that challenges
- The absence of predictability and structure

Develop a care plan with the child or young person and their families or carers that outlines the steps needed to address the factors that may provoke behaviour that challenges, including:

- Treatment, for example, for coexisting physical, mental health, and behavioural problems
- Support, for example, for families or carers
- Necessary adjustments, for example, by increasing structure and minimising unpredictability

Assessment and Initial Intervention for Behaviour That Challenges

If a child or young person's behaviour becomes challenging, reassess factors identified in the care plan and assess for any new factors that could

provoke the behaviour.

Offer the following to address factors that may trigger or maintain behaviour that challenges:

- Treatment for physical disorders, or coexisting mental health and behavioural problems
- Interventions aimed at changing the environment, such as:
 - Providing advice to families and carers
 - Making adjustments or adaptations to the physical surroundings (see "Making Adjustments to the Social and Physical Environment and Processes of Care," above)

If behaviour remains challenging despite attempts to address the underlying possible causes, consult senior colleagues and undertake a multidisciplinary review.

At the multidisciplinary review, take into account the following when choosing an intervention for behaviour that challenges:

- The nature, severity and impact of the behaviour
- The child or young person's physical and communication needs and capabilities
- The environment
- The support and training that families, carers or staff may need to implement the intervention effectively
- The preferences of the child or young person and the family or carers
- The child or young person's experience of, and response to, previous interventions

Psychosocial Interventions for Behaviour That Challenges

If no coexisting mental health or behavioural problem, physical disorder, or environmental problem has been identified as triggering or maintaining the behaviour that challenges, offer the child or young person a psychosocial intervention (informed by a functional assessment of behaviour) as a first-line treatment.

The functional assessment should identify:

- Factors that appear to trigger the behaviour
- Patterns of behaviour
- The needs that the child or young person is attempting to meet by performing the behaviour
- The consequences of the behaviour (that is, the reinforcement received as a result of the behaviour)

Psychosocial interventions for behaviour that challenges should include:

- Clearly identified target behaviour
- A focus on outcomes that are linked to quality of life
- Assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour
- A clearly defined intervention strategy that takes into account the developmental level and coexisting problems of the child or young person
- A specified timescale to meet intervention goals (to promote modification of intervention strategies that do not lead to change within a specified time)
- A systematic measure of the target behaviour taken before and after the intervention to ascertain whether the agreed outcomes are being met
- Consistent application in all areas of the child or young person's environment (for example, at home and at school)
- Agreement among parents, carers and professionals in all settings about how to implement the intervention

Pharmacological Interventions for Behaviour That Challenges

Consider antipsychotic medication¹ for managing behaviour that challenges in children and young people with autism when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour. Antipsychotic medication should be initially prescribed and monitored by a paediatrician or psychiatrist who should:

- Identify the target behaviour.
- Decide on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact.
- Review the effectiveness and any side effects of the medication after 3 to 4 weeks.
- Stop treatment if there is no indication of a clinically important response at 6 weeks.

If antipsychotic medication is prescribed:

- Start with a low dose.
- Use the minimum effective dose needed.
- Regularly review the benefits of the antipsychotic medication and any adverse events.

When choosing antipsychotic medication, take into account side effects, acquisition costs, the child or young person's preference (or that of their parent or carer where appropriate), and response to previous treatment with an antipsychotic.

When prescribing is transferred to primary or community care, the specialist should give clear guidance to the practitioner who will be responsible for continued prescribing about:

- The selection of target behaviours
- Monitoring of beneficial and side effects
- The potential for minimally effective dosing
- The proposed duration of treatment
- Plans for stopping treatment

¹At the time of publication (August 2013), no antipsychotic medication had a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Good practice in prescribing and managing medicines and devices](#) for further information.

Interventions for Life Skills

Offer children and young people with autism support in developing coping strategies and accessing community services, including developing skills to access public transport, employment, and leisure facilities.

Interventions for Autism That Should Not Be Used

Do not use neurofeedback to manage speech and language problems in children and young people with autism.

Do not use auditory integration training to manage speech and language problems in children and young people with autism.

Do not use omega-3 fatty acids to manage sleep problems in children and young people with autism.

Do not use the following interventions to manage autism in any context in children and young people:

- Secretin
- Chelation
- Hyperbaric oxygen therapy

Interventions for Coexisting Problems

Offer psychosocial and pharmacological interventions for the management of coexisting mental health or medical problems in children and young people with autism in line with NICE guidance for children and young people, including:

- The NGC summary of the NICE guideline [Attention deficit hyperactivity disorder. Diagnosis and management of ADHD in children, young people and adults](#) (NICE clinical guideline 72)
- The NGC summary of the NICE guideline [Antisocial behaviour and conduct disorders in children and young people: recognition, intervention and management](#) (NICE clinical guideline 158)
- The NICE guideline [Constipation in children and young people. Diagnosis and management of idiopathic childhood constipation in primary and secondary care](#) (NICE clinical guideline 99)
- [Depression in children and young people: identification and management in primary, community and secondary care](#) (NICE clinical guideline 28)
- The NGC summary of [The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care](#) (NICE clinical guideline 137)
- [Core interventions in the treatment of obsessive-compulsive disorder and body dysmorphic disorder](#) (NICE clinical guideline 31)

- [Post-traumatic stress disorder: The management of PTSD in adults and children in primary and secondary care](#)
(NICE clinical guideline 26)

Consider the following for children and young people with autism and anxiety who have the verbal and cognitive ability to engage in a cognitive behavioural therapy (CBT) intervention:

- Group CBT adjusted to the needs of children and young people with autism
- Individual CBT for children and young people who find group-based activities difficult

Consider adapting the method of delivery of CBT for children and young people with autism and anxiety to include:

- Emotion recognition training
- Greater use of written and visual information and structured worksheets
- A more cognitively concrete and structured approach
- Simplified cognitive activities, for example, multiple-choice worksheets
- Involving a parent or carer to support the implementation of the intervention, for example, involving them in therapy sessions
- Maintaining attention by offering regular breaks
- Incorporating the child or young person's special interests into therapy if possible

Interventions for Sleep Problems

If a child or young person with autism develops a sleep problem offer an assessment that identifies:

- What the sleep problem is (for example, delay in falling asleep, frequent waking, unusual behaviours, breathing problems or sleepiness during the day)
- Day and night sleep patterns, and any change to those patterns
- Whether bedtime is regular
- What the sleep environment is like, for example:
 - The level of background noise
 - Use of a blackout blind
 - A television or computer in the bedroom
 - Whether the child shares the room with someone
- Presence of comorbidities especially those that feature hyperactivity or other behavioural problems
- Levels of activity and exercise during the day
- Possible physical illness or discomfort (for example, reflux, ear or toothache, constipation, or eczema)
- Effects of any medication
- Any other individual factors thought to enhance or disturb sleep, such as emotional relationships or problems at school
- The impact of sleep and behavioural problems on parents or carers and other family members

If the child or young person with autism snores loudly, chokes, or appears to stop breathing while sleeping, refer to a specialist to check for obstructive sleep apnoea.

Develop a sleep plan (this will often be a specific sleep behavioural intervention) with the parents or carers to help address the identified sleep problems and to establish a regular night-time sleep pattern. Ask the parents or carers to record the child or young person's sleep and wakefulness throughout the day and night over a 2-week period. Use this information to modify the sleep plan if necessary and review the plan regularly until a regular sleep pattern is established.

Do not use a pharmacological intervention to aid sleep unless:

- Sleep problems persist despite following the sleep plan.
- Sleep problems are having a negative impact on the child or young person and their family or carers.

If a pharmacological intervention is used to aid sleep it should:

- Only be used following consultation with a specialist paediatrician or psychiatrist with expertise in the management of autism or paediatric sleep medicine
- Be used in conjunction with non-pharmacological interventions
- Be regularly reviewed to evaluate the ongoing need for a pharmacological intervention and to ensure that the benefits continue to outweigh the side effects and risks

If the sleep problems continue to impact on the child or young person or their parents or carers, consider:

- Referral to a paediatric sleep specialist and
- Short breaks and other respite care for one night or more. Short breaks may need to be repeated regularly to ensure that parents or carers are adequately supported. Agree the frequency of breaks with them and record this in the care plan.

Transition to Adult Services

Local autism teams should ensure that young people with autism who are receiving treatment and care from child and adolescent mental health services (CAMHS) or child health services are reassessed at around 14 years to establish the need for continuing treatment into adulthood.

If continuing treatment is necessary, make arrangements for a smooth transition to adult services and give information to the young person about the treatment and services they may need.

The timing of transition may vary locally and individually but should usually be completed by the time the young person is 18 years. Variations should be agreed by both child and adult services.

As part of the preparation for the transition to adult services, health and social care professionals should carry out a comprehensive assessment of the young person with autism.

The assessment should make best use of existing documentation about personal, educational, occupational, social, and communication functioning, and should include assessment of any coexisting conditions, especially depression, anxiety, ADHD, obsessive-compulsive disorder (OCD), and global delay or intellectual disability in line with the NGC summary of the NICE guideline [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum](#) (NICE clinical guideline 142).

For young people aged 16 or older whose needs are complex or severe, use the care programme approach in England, or care and treatment plans in Wales, as an aid to transfer between services.

Involve the young person in the planning and, where appropriate, their parents or carers.

Provide information about adult services to the young person, and their parents or carers, including their right to a social care assessment at age 18.

During transition to adult services, consider a formal meeting involving health and social care and other relevant professionals from child and adult services.

Definitions:

Strength of Recommendations

Some recommendations can be made with more certainty than others. The Guideline Development Group (GDG) makes a recommendation based on the trade-off between the benefits and harms of an intervention, taking into account the quality of the underpinning evidence. For some interventions, the GDG is confident that, given the information it has looked at, most patients would choose the intervention. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

Interventions That Must (or Must Not) Be Used

The GDG usually uses 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally 'must' (or 'must not') is used if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

Interventions That Should (or Should Not) Be Used – a 'Strong' Recommendation

The GDG uses 'offer' (and similar words such as 'refer' or 'advise') when confident that, for the vast majority of patients, an intervention will do more good than harm, and be cost effective. Similar forms of words (for example, 'Do not offer...') are used when the GDG is confident that an intervention will not be of benefit for most patients.

Interventions That Could Be Used

The GDG uses 'consider' when confident that an intervention will do more good than harm for most patients, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the patient's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the patient.

Clinical Algorithm(s)

A National Institute for Health and Care Excellence (NICE) pathway titled "Autism Overview" is available from the [NICE Web site](#)

Scope

Disease/Condition(s)

The autism spectrum

Other Disease/Condition(s) Addressed

- Anxiety
- Depression
- Sleep problems

Guideline Category

Counseling

Evaluation

Management

Prevention

Risk Assessment

Treatment

Clinical Specialty

Family Practice

Neurology

Nutrition

Pediatrics

Physical Medicine and Rehabilitation

Preventive Medicine

Psychiatry

Psychology

Speech-Language Pathology

Intended Users

Advanced Practice Nurses

Allied Health Personnel

Dietitians

Health Care Providers

Nurses

Occupational Therapists

Other

Patients

Physician Assistants

Physicians

Psychologists/Non-physician Behavioral Health Clinicians

Public Health Departments

Social Workers

Speech-Language Pathologists

Guideline Objective(s)

To provide best practice advice on the management and support of children and young people on the autism spectrum

Target Population

Children and young people (from birth until their 19th birthday) with autism (across the full range of intellectual ability) and their families and carers

Note: These guidelines do not apply to adults (19 years and older).

Interventions and Practices Considered

1. Patient access to health and social care services, including mental health services
2. Local autism team approach and specialist care with appropriate training
3. Adjustments to social and physical environment
 - Visual supports
 - Personal space
 - Sensory sensitivities to light, noise, colour of walls and furnishings
4. Adjustment to health and social care processes, including timing and location of appointments
5. Patient, family and carer involvement in decision-making
6. Psychosocial interventions
 - Play-based strategies
 - Therapist modelling and video-interaction feedback
7. Anticipation and prevention of challenging behavior
 - Assessment of factors (e.g., coexisting physical disorders or mental problems, exploitation or abuse by others)
 - Development of a care plan to address risk factors
8. Assessment of and intervention for challenging behavior
 - Reassessment of factors in the care plan
 - Treatment of coexisting physical disorders or mental problems
 - Consultation and multidisciplinary review
 - Psychosocial interventions

- Pharmacological therapy (antipsychotic medication)
9. Interventions for coexisting problems
 - Cognitive behavioural therapy (CBT)
 - Identification and treatment of sleep problems
 10. Transition to adult services
 11. Information and support for families and carers

Note: The following were considered but not recommended: pharmacological therapy for the core features of autism; neurofeedback and auditory integration training to manage speech and language problems; omega-3 fatty acids to manage sleep problems; secretin, chelation, and hyperbaric oxygen therapy in any context.

Major Outcomes Considered

- Quality of life
- Adverse effects of treatment drugs
- Experience of care, including experience of services and transition
- Cost-effectiveness (e.g., quality-adjusted life year)

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Searches of Unpublished Data

Description of Methods Used to Collect/Select the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Care Excellence (NICE) (see the "Availability of Companion Documents" field for the full version of this guidance).

Review Questions

Review (clinical) questions were used to guide the identification and interrogation of the evidence base relevant to the topic of the guideline. Before the first Guideline Development Group (GDG) meeting, an analytic framework (see Appendix 5 in the full version of the original guideline document) was prepared by NCCMH staff based on the scope (and an overview of existing guidelines), and discussed with the guideline Chair. The framework was used to provide a structure from which the review questions were drafted. Both the analytic framework and the draft review questions were then discussed by the GDG at the first few meetings and amended as necessary. Where appropriate, the framework and questions were refined once the evidence had been searched and, where necessary, sub-questions were generated. The final list of review questions can be found in Appendix 6 in the full version of the original guideline document.

For questions about interventions, the PICO (Population, Intervention, Comparison, and Outcome) framework was used (see Table 2 in the full version of the original guideline document). Although service user experience is a component of all review questions, specific questions concerning what the experience of care is like for children and young people with autism, and where appropriate, their families/carers, were developed by the GDG.

To help facilitate the literature review, a note was made of the best study design type to answer each question. There are four main types of review question of relevance to NICE guidelines. These are listed in Table 3 in the full version of the original guideline document. For each type of question, the best primary study design varies, where 'best' is interpreted as 'least likely to give misleading answers to the question'.

However, in all cases, a well-conducted systematic review (of the appropriate type of study) is likely to always yield a better answer than a single study. The use of evidence from inferior study designs may be necessary and usually depends on the availability of high-quality evidence (further information can be found in each evidence chapter in the full version of the original guideline document).

Systematic Clinical Literature Review

The Review Process

Scoping Searches

A broad preliminary search of the literature was undertaken in May 2011 to obtain an overview of the issues likely to be covered by the scope, and to help define key areas. Searches were restricted to clinical guidelines, Health Technology Assessment (HTA) reports, key systematic reviews, and randomised controlled trials (RCTs) and conducted in the following databases and websites:

- British Medical Journal (BMJ) Clinical Evidence
- Canadian Medical Association (CMA) Infobase (Canadian guidelines)
- Clinical Policy and Practice Program of the New South Wales Department of Health (Australia)
- Clinical Practice Guidelines (Australian Guidelines)
- Cochrane Central Register of Controlled Trials (CENTRAL)
- Cochrane Database of Abstracts of Reviews of Effects (DARE)
- Cochrane Database of Systematic Reviews (CDSR)
- Excerpta Medica Database (EMBASE)
- Guidelines International Network (G-I-N)
- Health Evidence Bulletin Wales
- Health Management Information Consortium (HMIC)
- HTA database (technology assessments)
- Medical Literature Analysis and Retrieval System Online (MEDLINE/MEDLINE in Process)
- National Health and Medical Research Council (NHMRC)
- National Library for Health (NLH) Guidelines Finder
- New Zealand Guidelines Group
- National Health Service (NHS) Centre for Reviews and Dissemination (CRD)
- Organizing Medical Networked Information (OMNI) Medical Search
- Scottish Intercollegiate Guidelines Network (SIGN)
- Turning Research Into Practice (TRIP)
- United States Agency for Healthcare Research and Quality (AHRQ)
- Websites of NICE– including NHS Evidence - and the National Institute for Health Research (NIHR) HTA Programme for guidelines and HTAs in development

Further information about this process can be found in The Guidelines Manual (NICE, 2012; see the "Availability of Companion Documents" field).

Systematic Literature Searches

After the scope was finalised, a systematic search strategy was developed to locate as much relevant evidence as possible. The balance between sensitivity (the power to identify all studies on a particular topic) and specificity (the ability to exclude irrelevant studies from the results) was carefully considered, and a decision made to utilise a broad approach to searching to maximise retrieval of evidence to all parts of the guideline. Searches were restricted to systematic reviews, RCTs, qualitative and survey research and conducted in the following databases:

- Australian Education Index (AEI)
- Applied Social Services Index and Abstracts (ASSIA)
- British Education Index (BEI)
- CDSR
- CENTRAL
- Cumulative Index to Nursing and Allied Health Literature (CINAHL)
- DARE
- Education Resources in Curriculum (ERIC)
- EMBASE

- HMIC
- HTA
- International Bibliography of Social Science (IBSS)
- Medline/Medline in process
- PsycINFO
- PsycEXTRA
- Social Policy and Practice (SPP)
- Social Services Abstracts
- Social Sciences Citation Index (SSCI)

The search strategies were initially developed for MEDLINE before being translated for use in other databases/interfaces. Strategies were built up through a number of trial searches and discussions of the results of the searches with the review team and GDG to ensure that all possible relevant search terms were covered. In order to assure comprehensive coverage, search terms for autism were kept purposely broad to help counter dissimilarities in database indexing practices and thesaurus terms, and imprecise reporting of study populations by authors in the titles and abstracts of records. The search terms for each search are set out in full in Appendix 7 in the full version of the original guideline document.

EndNote

Citations from each search were downloaded into the endnote software and duplicates removed. Records were then screened against the eligibility criteria of the reviews before being quality appraised (see the "Description of Methods Used to Analyze the Evidence" field). The unfiltered search results were saved and retained for future potential re-analysis to help keep the process both replicable and transparent.

Search Filters

To aid retrieval of relevant and sound studies, filters were used to limit a number of searches to systematic reviews, RCTs, qualitative and survey research. The search filters for systematic reviews and RCTs are adaptations of filters designed by Health Information Research Unit of McMaster University. The qualitative research filter was developed in-house. Each filter comprises index terms relating to the study type(s) and associated text words for the methodological description of the design(s).

Date and Language Restrictions

Systematic database searches were initially conducted in May 2011 up to the most recent searchable date. Search updates were generated on a 6-monthly basis, with the final re-runs carried out in January 2013 ahead of the guideline consultation. After this point, studies were only included if they were judged by the GDG to be exceptional (for example, if the evidence was likely to change a recommendation).

Although no language restrictions were applied at the searching stage, foreign language papers were not requested or reviewed, unless they were of particular importance to a review question.

Date restrictions were not applied, except for searches for systematic reviews, and experience of care, which were limited to research published from 1995 onwards, since older research was thought to be less useful.

Other Search Methods

Other search methods involved: (a) scanning the reference lists of all eligible publications (systematic reviews, stakeholder evidence, and included studies) for more published reports and citations of unpublished research; (b) checking the tables of contents of key journals for studies that might have been missed by the database and reference list searches; (c) tracking key papers in the Science Citation Index (prospectively) over time for further useful references; (d) conducting searches of the 'Research Autism', ISRCTN, and ClinicalTrials.gov websites for unpublished trial reports; (e) contacting included study authors for unpublished or incomplete data sets. Searches conducted for existing NICE guidelines were updated where necessary. Other relevant guidelines were assessed for quality using the Appraisal of Guidelines for Research and Evaluation (AGREE) instrument (AGREE Collaboration, 2003). The evidence base underlying high-quality existing guidelines was utilised and updated as appropriate.

Full details of the search strategies and filters used for the systematic review of clinical evidence are provided in Appendix 7 in the full version of the original guideline document.

Study Selection and Quality Assessment

All primary-level studies included after the first scan of citations were acquired in full and re-evaluated for eligibility at the time they were being entered into the study information database. More specific eligibility criteria were developed for each review question and are described in the relevant clinical evidence chapters in the full version of the original guideline document. Eligible systematic reviews and primary-level studies were

critically appraised for risk of bias (see The Guidelines Manual [NICE, 2012] for the methodology checklist templates). The eligibility of each study was confirmed by at least one member of the GDG.

Unpublished Evidence

Authors and principal investigators were approached for unpublished evidence (see Appendix 4 in the full version of the original guideline document). The GDG used a number of criteria when deciding whether or not to accept unpublished data. First, the evidence must have been accompanied by a trial report containing sufficient detail to properly assess the quality of the data. Second, the evidence must have been submitted with the understanding that data from the study and a summary of the study's characteristics would be published in the full guideline. Therefore, the GDG did not accept evidence submitted as commercial in confidence. However, the GDG recognised that unpublished evidence submitted by investigators might later be retracted by those investigators if the inclusion of such data would jeopardise publication of their research.

Health Economic Methods

The aim of the health economics was to contribute to the guideline's development by providing evidence on the cost effectiveness of interventions for the management and support of children and young people with autism and their families covered in the guideline.

Systematic reviews of economic literature were conducted in all areas covered in the guideline. In addition, literature on the health-related quality of life of children and young people with autism was systematically searched to identify studies reporting appropriate utility scores that could be utilised in a cost-utility analysis.

Inclusion Criteria for Economic Studies

The following inclusion criteria were applied to select studies identified by the economic searches for further consideration:

- Only studies from Organisation for Economic Co-operation and Development countries were included, as the aim of the review was to identify economic information transferable to the UK context.
- Selection criteria based on types of clinical conditions and service users as well as interventions assessed were identical to the clinical literature review.
- Studies were included provided that sufficient details regarding methods and results were available to enable the methodological quality of the study to be assessed, and provided that the study's data and results were extractable. Conference abstracts or poster presentations were excluded.
- Full economic evaluations that compared two or more relevant options and considered both costs and consequences as well as costing analyses that compared only costs between two or more interventions were included in the review.
- Economic studies were included if they used clinical effectiveness data either from a single study (a clinical trial, a cohort study, a study with a mirror-image design etc) or from a literature review of primary studies.
- Non-UK Studies that reported exclusively intervention costs, without any other cost implications, were excluded from consideration as this information was deemed not useful or relevant to the UK setting.

Results of the Systematic Search of Economic Literature

The titles of all studies identified by the systematic search of the literature were screened for their relevance to the topic (that is, economic issues and information on the health-related quality of life in children and young people with autism). References that were clearly not relevant were excluded first. The abstracts of all potentially relevant studies (116 references) were then assessed against the inclusion criteria for economic evaluations by the health economist. Full texts of the studies potentially meeting the inclusion criteria (including those for which eligibility was not clear from the abstract) were obtained. Studies that did not meet the inclusion criteria, were duplicates, were secondary publications of one study, or had been updated in more recent publications were subsequently excluded. Economic evaluations eligible for inclusion (6 references) were then appraised for their applicability and quality using the methodology checklist for economic evaluations. Three economic studies identified by the systematic literature search, as well as one study that was unpublished at the time of the guideline development and was identified through consultation with the GDG, met fully or partially the applicability and quality criteria for economic studies, and were thus considered at formulation of the guideline recommendations.

Number of Source Documents

Not stated

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Overall Quality of Outcome Evidence in Grading of Recommendations Assessment, Development and Evaluation (GRADE)

Level	Description
High	Further research is very unlikely to change confidence in the estimate of effect
Moderate	Further research is likely to have an important impact on confidence in the estimate of effect and may change the estimate
Low	Further research is very likely to have an important impact on confidence in the estimate of effect and is likely to change the estimate
Very Low	Any estimate of effect is very uncertain

Methods Used to Analyze the Evidence

Meta-Analysis

Review of Published Meta-Analyses

Systematic Review with Evidence Tables

Description of the Methods Used to Analyze the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Care Excellence (NICE) (see the "Availability of Companion Documents" field for the full version of this guidance).

Systematic Clinical Literature Review

Data Extraction

Quantitative Analysis

Study characteristics, methodological quality, and outcome data were extracted from all eligible studies that met the minimum quality criteria, using Review Manager 5.1 (The Cochrane Collaboration, 2011) and Excel-based forms (see Appendix 12 in the full version of the original guideline document).

In most circumstances, for a given outcome (continuous and dichotomous), where more than 50% of the number randomised to any group were missing or incomplete, the study results were excluded from the analysis (except for the outcome 'leaving the study early', in which case, the denominator was the number randomised). Where there was limited data for a particular review, the 50% rule was not applied. In these circumstances the evidence was downgraded due to the risk of bias.

Where possible, outcome data from an intention-to-treat (ITT) analysis (that is, a 'once-randomised-always-analyse' basis) were used. Adverse effects were entered into Review Manager as reported by the study authors because it is usually not possible to determine whether early withdrawals had an unfavourable outcome.

Consultation with another reviewer or members of the Guideline Development Group (GDG) was used to overcome difficulties with coding. Data from studies included in existing systematic reviews were extracted independently by one reviewer and cross-checked with the existing dataset. Where possible, two independent reviewers extracted data from new studies. Where double data extraction was not possible, data extracted by one reviewer was checked by the second reviewer. Disagreements were resolved through discussion. Where consensus could not be reached, a

third reviewer or GDG members resolved the disagreement. Masked assessment (that is, blind to the journal from which the article comes, the authors, the institution, and the magnitude of the effect) was not used since it is unclear that doing so reduces bias.

Qualitative Analysis

After transcripts or reviews of service user experience were identified (see the "Descriptions of Methods Used to Collect/Select the Evidence" field), each was read and re-read and sections of the text were collected under different headings using an Excel-based form. Initially the text from the transcripts/reviews was organised using a matrix of service user experience (see Table 4 in the full version of the original guideline document).

A matrix was formed by creating a table with the eight dimensions of patient-centred care developed by the Picker Institute Europe (see Table 4 in the full version of the original guideline document for further information), down the vertical axis, and the key points on a pathway of care (as specified by the GDG before data extraction) across the horizontal axis. With regard to terminology, the GDG preferred the term 'person-centred' rather than 'patient-centred', therefore the former is used in the matrix. The Picker Institute's dimensions of patient-centred care were chosen because they are well established, comprehensive, and based on research. In addition, a variation of these dimensions has been adopted by the US Institute of Medicine.

Under the broad headings in the matrix, specific emergent themes were identified and coded by two researchers working independently. Overlapping themes and themes with the highest frequency count across all testimonies were extracted and regrouped using the matrix. The findings from this qualitative analysis can be found in Chapter 4 in the full version of the original guideline document.

Expert Advisory Group Validation for the Qualitative Evidence Review

It was not possible to have a child or young person service user as a regular GDG member, due in part to the time demands of the GDG member role and problems associated with the group-based environment and format of GDG meetings, so the results of the qualitative analysis were instead presented by the National Autistic Society (NAS) to an expert advisory group of children and young people with autism recruited from a number of different settings to validate the conclusions of the analysis.

Material from these focus groups or individual interviews was used to supplement the literature review of service user and carer experience of care and organisation and delivery of care. This enabled a triangulation of the service user and carer experience findings – that is, the guideline authors were able to compensate for possible weaknesses in one data collection or analysis method by using additional methods, in this case, material from a systematic qualitative literature review was combined with that from focus groups and individual sessions conducted by the NAS.

Synthesising the Evidence for Intervention Effectiveness

Meta-analysis

Where possible, meta-analysis was used to synthesise evidence for the effectiveness of interventions using Review Manager. If necessary, re-analyses of the data or sub-analyses were used to answer review questions not addressed in the original studies or reviews.

Dichotomous outcomes were analysed as relative risks (RRs) or odds ratios (ORs) with the associated 95% confidence interval (CI) (see Figure 1 in the full version of the original guideline document for an example of a forest plot displaying dichotomous data). A RR (also called a risk ratio) is the ratio of the treatment event rate to the control event rate. A RR of 1 indicates no difference between treatment and control. The overall RR in Figure 1 (see the full version of the original guideline document) of 0.73 indicates that the event rate (that is, non-remission rate) associated with intervention A is about three-quarters of that with the control intervention or, in other words, the relative risk reduction is 27%.

Heterogeneity

To check for consistency of effects among studies, both the I^2 statistic and the chi-squared test of heterogeneity, as well as a visual inspection of the forest plots were used. The I^2 statistic describes the proportion of total variation in study estimates that is due to heterogeneity. For a meta-analysis of comparative effectiveness studies, the I^2 statistic was interpreted in the following way based on Higgins and Green (2011):

- 0% to 40%: might not be important
- 30% to 60%: may represent moderate heterogeneity
- 50% to 90%: may represent substantial heterogeneity
- 75% to 100%: considerable heterogeneity

The Cochrane Collaboration advice suggests that overlapping categories are less misleading than simple thresholds since the importance of inconsistency depends on (1) the magnitude and direction of effects, and (2) the strength of evidence for heterogeneity (for example, p value from the chi-squared test, or a CI for I^2).

Publication Bias

Where there was sufficient data, funnel plots were used to explore the possibility of publication bias. Asymmetry of the plot would be taken to indicate possible publication bias and investigated further.

Where necessary, an estimate of the proportion of eligible data that were missing (because some studies did not include all relevant outcomes) was calculated for each analysis.

Grading the Quality of Evidence

For questions about interventions, the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach was used to grade the quality of evidence for each outcome. For questions about the experience of care and the organisation and delivery of care, methodology checklists (see "Data Extraction," above) were used to assess the risk of bias, and this information was taken into account when interpreting the evidence. The technical team produced GRADE evidence profiles (see below) using GRADEprofiler (GRADEpro) software (Version 3.6), following advice set out in the GRADE handbook.

Evidence Profiles

A GRADE evidence profile was used to summarise both the quality of the evidence and the results of the evidence synthesis for each 'critical' outcome (see Table 5 in the full version of the original guideline document for an example of an evidence profile). The GRADE approach is based on a sequential assessment of the quality of evidence, followed by judgment about the balance between desirable and undesirable effects, and subsequent decision about the strength of a recommendation.

Within the GRADE approach to grading the quality of evidence, the following is used as a starting point:

- Randomised trials without important limitations provide high quality evidence
- Observational studies without special strengths or important limitations provide low quality evidence

For each outcome, quality may be reduced depending on five factors: risk of bias, inconsistency, indirectness, imprecision, and publication bias. For the purposes of the guideline, each factor was evaluated using criteria provided in Table 6 in the full version of the original guideline document.

For observational studies without any reasons for down-grading, the quality may be up-graded if there is a large effect, all plausible confounding would reduce the demonstrated effect (or increase the effect if no effect was observed), or there is evidence of a dose-response gradient (details would be provided under the 'other' column).

Each evidence profile includes a summary of findings: number of participants included in each group, an estimate of the magnitude of the effect, and the overall quality of the evidence for each outcome. Under the GRADE approach, the overall quality for each outcome is categorised into one of four groups (high, moderate, low, very low).

Presenting Evidence to the Guideline Development Group

Study characteristics tables and, where appropriate, forest plots generated with Review Manager and GRADE Summary of Findings tables were presented to the GDG.

Where meta-analysis was not appropriate and/or possible, the reported results from each primary-level study were included in the study characteristics table. The range of effect estimates were included in the GRADE profile, and where appropriate, described narratively.

Health Economic Methods

The aim of the health economics was to contribute to the guideline's development by providing evidence on the cost effectiveness of interventions for the management and support of children and young people with autism and their families covered in the guideline. This was achieved by:

- Systematic literature review of existing economic evidence
- Decision-analytic economic modelling

Systematic reviews of economic literature were conducted in all areas covered in the guideline. Economic modelling was undertaken in areas with likely major resource implications, where the current extent of uncertainty over cost effectiveness was significant and economic analysis was expected to reduce this uncertainty, in accordance with The Guidelines Manual (NICE, 2012; see the "Availability of Companion Documents" field). Prioritisation of areas for economic modelling was a joint decision between the Health Economist and the Guideline Development Group. The rationale for prioritising review questions for economic modelling was set out in an economic plan agreed between the National Institute for Health and Care Excellence (NICE), the Guideline Development Group, the Health Economist, and the other members of the technical team. The

following economic questions were selected as key issues that were addressed by economic modelling:

- Cost effectiveness of interventions aimed at behaviour that challenges (focusing on antipsychotic medications)
- Cost effectiveness of interventions aimed at co-existing problems or disorders (focusing on cognitive behavioural therapy for the management of anxiety)

In addition, literature on the health-related quality of life of children and young people with autism was systematically searched to identify studies reporting appropriate utility scores that could be utilised in a cost-utility analysis.

Applicability and Quality Criteria for Economic Studies

All economic papers eligible for inclusion were appraised for their applicability and quality using the methodology checklist for economic evaluations recommended by NICE (NICE, 2012), which is shown in Appendix 10 in the full version of the original guideline document. The methodology checklist for economic evaluations was also applied to the economic models developed specifically for this guideline. All studies that fully or partially met the applicability and quality criteria described in the methodology checklist were considered during the guideline development process, along with the results of the economic modelling conducted specifically for this guideline. The completed methodology checklists for all economic evaluations considered in the guideline are provided in Appendix 15 in the full version of the original guideline document.

Methods Used to Formulate the Recommendations

Expert Consensus

Informal Consensus

Description of Methods Used to Formulate the Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Care Excellence (NICE) (see the "Availability of Companion Documents" field for the full version of this guidance).

The development of this guideline drew upon methods outlined by NICE (The Guidelines Manual [NICE, 2009] [see the "Availability of Companion Documents" field]). A team of health and social care professionals, lay representatives and technical experts known as the Guideline Development Group (GDG), with support from the NCCMH staff, undertook the development of a person-centred, evidence-based guideline.

Twelve GDG meetings were held between 9 December 2011 and 31 May 2013. During each day-long GDG meeting, in a plenary session, review questions and clinical and economic evidence were reviewed and assessed, and recommendations formulated.

The clinical practice recommendations made by the GDG are derived from the most up-to-date and robust evidence for the clinical and cost effectiveness of the treatments and services used in the treatment and management of autism. Where evidence was not found or was inconclusive, the GDG discussed and attempted to reach consensus on what should be recommended, factoring in any relevant issues. In addition, to ensure a service user and carer focus, the concerns of service users and carers regarding health and social care have been highlighted and addressed by recommendations agreed by the whole GDG.

From Evidence to Recommendations

Once the clinical and health economic evidence was summarised, the GDG drafted the recommendations. In making recommendations, the GDG took into account the trade-off between the benefits and harms of the intervention/instrument, as well as other important factors, such as economic considerations, values of the development group and society, the requirements to prevent discrimination and to promote equality, and the GDG's awareness of practical issues.

The GDG agreed a set of criteria between themselves for interpreting the clinical evidence and deciding on recommendations for interventions. The criteria for positive recommendations that the GDG considered appropriate were that there was data from more than one study (meta-analysis was possible), outcome assessment was blinded and the outcome was a direct outcome (target) of the intervention. For negative treatment recommendations the criteria threshold was lower as is appropriate for the clinical priority to first do no harm. 'Do not do' recommendations were based on evidence of significant adverse events and/or evidence of significant negative/placebo treatment effects.

Finally, to show clearly how the GDG moved from the evidence to the recommendations, each chapter has a section called 'from evidence to

recommendations'. Underpinning this section is the concept of the 'strength' of a recommendation (see the "Rating Scheme for the Strength of the Recommendations" field).

Rating Scheme for the Strength of the Recommendations

Strength of Recommendations

Some recommendations can be made with more certainty than others. The Guideline Development Group (GDG) makes a recommendation based on the trade-off between the benefits and harms of an intervention, taking into account the quality of the underpinning evidence. For some interventions, the GDG is confident that, given the information it has looked at, most patients would choose the intervention. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

Interventions That Must (or Must Not) Be Used

The GDG usually uses 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally 'must' (or 'must not') is used if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

Interventions That Should (or Should Not) Be Used – a 'Strong' Recommendation

The GDG uses 'offer' (and similar words such as 'refer' or 'advise') when confident that, for the vast majority of patients, an intervention will do more good than harm, and be cost effective. Similar forms of words (for example, 'Do not offer...') are used when the GDG is confident that an intervention will not be of benefit for most patients.

Interventions That Could Be Used

The GDG uses 'consider' when confident that an intervention will do more good than harm for most patients, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the patient's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the patient.

Cost Analysis

Presentation of Economic Evidence

The economic evidence considered in the guideline is provided in the respective evidence chapters, following presentation of the relevant clinical evidence. The references to included studies and the respective evidence tables with the study characteristics and results are provided in Appendix 16 of the full version of the original guideline document. Methods and results of economic modelling undertaken alongside the guideline development process are presented in the relevant evidence chapters. Characteristics and results of all economic studies considered during the guideline development process (including modelling studies conducted for this guideline) are summarised in economic evidence profiles accompanying respective Grading of Recommendations Assessment, Development and Evaluation (GRADE) clinical evidence profiles in Appendix 17 of the full version of the original guideline document.

The completed methodology checklists for all economic evaluations considered in the guideline are provided in Appendix 15 in the full version of the original guideline document.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

Validation of the Guideline

Registered stakeholders had an opportunity to comment on the draft guideline, which was posted on the National Institute for Health and Care

Excellence (NICE) website during the consultation period. Following the consultation, all comments from stakeholders and experts (see Appendix 3 in the full version of the original guideline document [see the "Availability of Companion Documents" field]) were responded to, and the guideline revised as appropriate. NICE also reviewed the guideline and checked that stakeholders' comments had been addressed.

Following the consultation period, the Guideline Development Group finalised the recommendations and the National Collaborating Centre for Mental Health (NCCMH) produced the final documents. These were then submitted to NICE for a quality assurance check. Any errors were corrected by the NCCMH, then the guideline was formally approved by NICE and issued as guidance to the National Health Service in England and Wales.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of evidence supporting the recommendations is not specifically stated.

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

Appropriate management and support of children and young people on the autism spectrum

See the "From Evidence to Recommendations" sections of the full version of the original guideline document for additional details about benefits of specific interventions.

Potential Harms

Side effects of medications

See the "From Evidence to Recommendations" sections and Chapter 9 in the full version of the original guideline document for additional details about potential harms of specific interventions.

Qualifying Statements

Qualifying Statements

- This guidance represents the view of the National Institute for Health and Care Excellence (NICE), which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summaries of product characteristics of any drugs.
- Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.
- Treatment and care should take into account individual needs and preferences. Patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If the patient is under 16, their family or carers should also be given information and support to help the child or young person to make decisions about their treatment. Healthcare professionals should follow the [Department of Health's advice on consent](#) . If someone does not have capacity to make decisions, healthcare professionals should follow the [code of practice that accompanies the Mental Capacity Act](#)

and the supplementary code of practice on deprivation of liberty safeguards. In Wales, healthcare professionals should follow [advice on consent from the Welsh Government](#) .

- If a young person is moving between paediatric and adult services, care should be planned and managed according to the best practice guidance described in the Department of Health's Transition: getting it right for young people.
- Adult and paediatric healthcare teams should work jointly to provide assessment and services to young people with autism. Diagnosis and management should be reviewed throughout the transition process, and there should be clarity about who is the lead clinician to ensure continuity of care.
- For all recommendations, NICE expects that there is discussion with the patient about the risks and benefits of the interventions, and their values and preferences. This discussion aims to help them to reach a fully informed decision.

See also the "Uses and Limitations of Clinical Guidelines" section in the full version of the original guideline document (see the "Availability of Companion Documents" field).

Implementation of the Guideline

Description of Implementation Strategy

The National Institute for Health and Care Excellence (NICE) has developed tools to help organisations implement this guidance. These are available on the [NICE Web site](#) (see also the "Availability of Companion Documents" field).

Key Priorities for Implementation

The following recommendations have been identified as priorities for implementation.

Access to Health and Social Care Services

- Ensure that all children and young people with autism have full access to health and social care services, including mental health services, regardless of their intellectual ability or any coexisting diagnosis.

Knowledge and Competence of Health and Social Care Professionals

- Health and social care professionals working with children and young people with autism in any setting should receive training in autism awareness and skills in managing autism, which should include:
 - The nature and course of autism
 - The nature and course of behaviour that challenges in children and young people with autism
 - Recognition of common coexisting conditions, including:
 - Mental health problems such as anxiety and depression
 - Physical health problems such as epilepsy
 - Sleep problems
 - Other neurodevelopmental conditions such as attention deficit hyperactivity disorder (ADHD)
 - The importance of key transition points, such as changing schools or health or social care services
 - The child or young person's experience of autism and its impact on them
 - The impact of autism on the family (including siblings) or carers
 - The impact of the social and physical environment on the child or young person
 - How to assess risk (including self-harm, harm to others, self-neglect, breakdown of family or residential support, exploitation, or abuse by others) and develop a risk management plan
 - The changing needs that arise with puberty (including the child or young person's understanding of intimate relationships and related problems that may occur, for example, misunderstanding the behaviour of others)
 - How to provide individualised care and support and ensure a consistent approach is used across all settings
 - Skills for communicating with a child or young person with autism

Making Adjustments to the Social and Physical Environment and Processes of Care

- Take into account the physical environment in which children and young people with autism are supported and cared for. Minimise any negative impact by:

- Providing visual supports, for example, words, pictures or symbols that are meaningful for the child or young person
- Making reasonable adjustments or adaptations to the amount of personal space given
- Considering individual sensory sensitivities to lighting, noise levels, and the colour of walls and furnishings
- Make adjustments or adaptations to the processes of health or social care, for example, arranging appointments at the beginning or end of the day to minimise waiting time, or providing single rooms for children and young people who may need a general anaesthetic in hospital (for example, for dental treatment).

Psychosocial Interventions

- Consider a specific social-communication intervention for the core features of autism in children and young people that includes play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person. Strategies should:
 - Be adjusted to the child or young person's developmental level
 - Aim to increase the parents', carers', teachers' or peers' understanding of, and sensitivity and responsiveness to, the child or young person's patterns of communication and interaction
 - Include techniques of therapist modelling and video-interaction feedback
 - Include techniques to expand the child or young person's communication, interactive play, and social routines
 The intervention should be delivered by a trained professional. For pre-school children consider parent, carer or teacher mediation. For school-aged children consider peer mediation.

Anticipating and Preventing Behaviour That Challenges

- Assess factors that may increase the risk of behaviour that challenges in routine assessment and care planning in children and young people with autism, including:
 - Impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes
 - Coexisting physical disorders, such as pain or gastrointestinal disorders
 - Coexisting mental health problems such as anxiety or depression and other neurodevelopmental conditions such as ADHD
 - The physical environment, such as lighting and noise levels
 - The social environment, including home, school and leisure activities
 - Changes to routines or personal circumstances
 - Developmental change, including puberty
 - Exploitation or abuse by others
 - Inadvertent reinforcement of behaviour that challenges
 - The absence of predictability and structure

Psychosocial Interventions for Behaviour That Challenges

- If no coexisting mental health or behavioural problem, physical disorder or environmental problem has been identified as triggering or maintaining the behaviour that challenges, offer the child or young person a psychosocial intervention (informed by a functional assessment of behaviour) as a first-line treatment.

Pharmacological Interventions for Behaviour That Challenges

- Consider antipsychotic medication¹ for managing behaviour that challenges in children and young people with autism when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour. Antipsychotic medication should be initially prescribed and monitored by a paediatrician or psychiatrist who should:
 - Identify the target behaviour.
 - Decide on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact.
 - Review the effectiveness and any side effects of the medication after 3 to 4 weeks.
 - Stop treatment if there is no indication of a clinically important response at 6 weeks.

¹At the time of publication (August 2013), no antipsychotic medication had a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Good practice in prescribing and managing medicines and devices](#) for further information.

Families and Carers

- Offer families (including siblings) and carers an assessment of their own needs, including whether they have:
 - Personal, social, and emotional support
 - Practical support in their caring role, including short breaks and emergency plans
 - A plan for future care for the child or young person, including transition to adult services

Transition to Adult Services

- For young people aged 16 or older whose needs are complex or severe, use the care programme approach (CPA) in England, or care and treatment plans in Wales, as an aid to transfer between services.
- Involve the young person in the planning and, where appropriate, their parents or carers.
- Provide information about adult services to the young person, and their parents or carers, including their right to a social care assessment at age 18.

From National Clinical Guidelines to Local Protocols

Once a national guideline has been published and disseminated, local healthcare groups will be expected to produce a plan and identify resources for implementation, along with appropriate timetables. Subsequently, a multidisciplinary group involving commissioners of healthcare, primary care, and specialist mental health professionals, service users, and carers should undertake the translation of the implementation plan into local protocols, taking into account both the recommendations set out in this guideline and the priorities in the National Service Framework for Mental Health and related documentation. The nature and pace of the local plan will reflect local healthcare needs and the nature of existing services; full implementation may take a considerable time, especially where substantial training needs are identified.

Implementation Tools

Clinical Algorithm

Mobile Device Resources

Patient Resources

Resources

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Living with Illness

Staying Healthy

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

National Collaborating Centre for Mental Health. Autism. The management and support of children and young people on the autism spectrum. London (UK): National Institute for Health and Care Excellence (NICE); 2013 Aug. 36 p. (Clinical guideline; no. 170).

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

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Guideline Developer(s)

National Collaborating Centre for Mental Health - National Government Agency [Non-U.S.]

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National Institute for Health and Care Excellence (NICE)

Guideline Committee

Guideline Development Group

Composition of Group That Authored the Guideline

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Financial Disclosures/Conflicts of Interest

All Guideline Development Group (GDG) members made formal declarations of interest at the outset, which were updated at every GDG meeting and service user and carer concerns were routinely discussed as a standing agenda item. See Appendix 2 in the full version of the original guideline document (see the "Availability of Companion Documents" field) for declarations of interests by GDG members.

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Guideline Availability

Electronic copies: Available from the [National Institute for Health and Care Excellence \(NICE\) Web site](#) . Also available for download as a Kindle or EPUB ebook from the [NICE Web site](#) .

Availability of Companion Documents

The following are available:

- Autism. The management and support of children and young people on the autism spectrum. Full guideline. London (UK): National Institute for Health and Care Excellence (NICE); 2013 Aug. 866 p. (Clinical guideline; no 170). Electronic copies: Available in Portable Document Format (PDF) from the [NICE Web site](#) .
- Autism. The management and support of children and young people on the autism spectrum. Appendices 1-13. London (UK): National Institute for Health and Care Excellence (NICE); 2013 Aug. (Clinical guideline; no 170). Electronic copies: Available in PDF from the [NICE Web site](#) .
- Autism. The management and support of children and young people on the autism spectrum. Appendices 14-19. London (UK): National Institute for Health and Care Excellence (NICE); 2013 Aug. (Clinical guideline; no 170). Electronic copies: Available in PDF from the [NICE Web site](#) .
- Autism. The management and support of children and young people on the autism spectrum. Baseline assessment tool. London (UK): National Institute for Health and Care Excellence (NICE); 2013 Aug. (Clinical guideline; no 170). Electronic copies: Available from the [NICE Web site](#) .
- Autism. The management and support of children and young people on the autism spectrum. Costing statement. London (UK): National Institute for Health and Care Excellence (NICE); 2013 Aug. 9 p. (Clinical guideline; no 170). Electronic copies: Available in PDF from the [NICE Web site](#) .
- Autism overview. NICE pathway. London (UK): National Institute for Health and Care Excellence (NICE); 2013 Aug. Electronic copies: Available from the [NICE Web site](#) .
- The guidelines manual 2009. London (UK): National Institute for Health and Care Excellence (NICE); 2009 Jan. Electronic copies: Available in PDF from the [NICE Archive Web site](#) .

Patient Resources

The following is available:

- Managing autism in children and young people. Information for the public. London (UK): National Institute for Health and Care Excellence (NICE); 2013 Aug. Electronic copies: Available from the [National Institute for Health and Care Excellence \(NICE\) Web site](#) . Also available for download as a Kindle or EPUB ebook from the [NICE Web site](#) .

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